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information &  
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to individuals with  
disabilities and  
their families  
as they direct their  
own supports and  
services



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## Taking Charge The Furrer Family in Real Life Choices

During the early years of raising their daughter, Stephanie, Gail and Jim Furrer were so busy dealing with every day issues that there wasn't much time for planning for the future. "I guess we were convinced that the only thing out there for Stephanie was a group home," admits Gail. "We didn't really give it much thought."

But in 1998, while Stephanie was still in school, Gail took part in "Project Take Charge", a unique self-advocacy training program sponsored by the Council on Developmental Disabilities. Immediately following that experience, Gail enrolled in "Partners in Policy Making," an eight month advocacy program also funded by the Council. "Take Charge really changed the way we looked at things," says Gail. "We realized had had other options. We realized that 'the problem' wasn't Stephanie, the problem was the way we were looking at her."

*"With a pilot, you have to expect these things; you have to be patient."*

*"Everyone, even DDD, is still learning how to do this."*

Stephanie, now 24, graduated from the Bancroft School in 2004. Gail describes her as having a rare genetic disorder that resulted in multiple disabilities including epilepsy, cerebral palsy, mental retardation and a heart condition.

Knowing the lack of adult services for someone with Stephanie's needs, Gail and Jim started looking for a day program for Stephanie when she was about 14. "We settled on a program that would accept her, but to be honest, it just didn't seem right for her," said Gail. "I felt like we didn't have much of a choice."

But soon after that, things turned around for the Furrers. "I got a call from DDD informing us of an opening in an adult training center with a special needs focus," said Gail. "We took it. I am thrilled with the program and have a good relationship with the people who run it."

Last winter, Gail received a call from her DDD case manager. "I guess Steph's number on the residential waiting list was up and there was a placement for her. They wanted to know if we would accept placement," said Gail. But the Furrers were not ready. "We said absolutely not. I told my case manager that we wanted to keep her home but we needed supports."

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Soon after, they got a call about Real Life Choices.

“We went to a meeting and signed up immediately,” said Gail. “DDD assigned us a support broker—but we were ready and knew what we wanted.” Within a month, they got started.

Because of the nature of her needs, Stephanie receives the highest category of funding. Although far less than the cost of a residential program, the Furrers feel that Stephanie’s budget is adequate for her needs and those of the family at this point in time. They are able to purchase Stephanie’s day program, which includes the specialized transportation she needs, respite care services through a provider agency, four weeks of summer and a lift for the bath tub.

“We are thrilled with Real Life Choices and what it has meant for our family,” said Gail. “The budget lets us do so many wonderful things and lets us keep Steph home with us, which is what we want. Step is always happy as long as she is busy. RLC has made our whole family more comfortable, and if we are less stressed, life is better for her.”

While the experience with RLC has been a positive one for the Furrers, it has not been without challenges. In less than a year, Gail has become very familiar with some of the Medicaid rules that steer community services through RLC.

“Real Life Choices is not a ‘what ever it takes’ program,” she laughs. “Its ‘what ever it takes within the rules. There are still some kinks to work out.”

Case in point: The Furrers knew they wanted their daughter to go to a specialized four week summer camp, but the broker assigned to them said the camp they chose could not be approved because it was out of state. “We wrote letters and made a number of phone calls back and forth to DDD and the support broker. I told them, ‘look, we are not getting many real life choices here’.” Ultimately, DDD approved funding for the camp and Stephanie was able to attend.

Gail takes challenges like this in stride. “With a pilot, you have to expect these things; you have to be patient. Everyone, even DDD, is still learning how to do this.”

The next project, it was getting a lift for the bathtub. “Steph has poor balance,” says Gail. “If she is going to live at home, we needed a tub lift to get her in and out of the bath every day.” At first, DDD told the Furrers that that a tub lift could

not be funded through RLC because it is considered a durable medical good and, not a Medicaid-funded service. It was suggested that they use part of Stephanie’s budget to hire someone to lift her in and out every day. “But I did the math for them,” says Gail. “A staff person to do that every day would cost four times more than the \$1,600 we needed for a lift.” After some advocacy on Gail’s part, the lift was funded. “As I said, there are some kinks to be worked out,” said Gail, “but I have found that if you have good argument, you keep at it, and it makes sense, you can probably get funded.”

Now, Gail is facing another administrative barrier linked to federal funding rules. This time, it concerns full access to community inclusion.

“...By asking questions directly and advocating for systems change, Gail hopes Real Life Choices can be improved for everyone.”

“Stephanie has always been out in the community,” explains Gail. “We made it a point to have her included in everything we do. People recognize her more than they do us. We are ‘Stephanie’s parents.’ It is not surprising, then, that the Furrers want Stephanie’s staff to take her out in the community. But, according to Gail, a Medicaid rule prohibits staff from being paid for food or shelter. This means that if one of Stephanie’s staff take her for dinner or provide support for her on a family vacation, restaurant meals and hotel accommodations for the staff must not be paid for out of Stephanie’s budget. “How can I ask a worker to take Stephanie to dinner at Applebee’s but then ask them to pay for their own dinner?”

Some of these rules don’t make sense to Gail, especially in light of Medicaid’s Community Care Waiver, which is intended to allow states to use federal dollars to fund support services in the community.

Gail hopes that by asking the questions directly and advocating for system change, the program can be improved for everyone.”

Gail’s perspective doesn’t come as a surprise. It is that “Take Charge” approach to advocacy that set her and her family down this road to self-directed services in the first place.

# It's All About Relationships

by Dan Baker, Ph.D.

*Editor's Note: This is the third in a periodic series of articles highlighting information shared at the Boggs Center's "Gathering" on self-directed services.*

The specific relationship among people with disabilities and the staff who support them can be very complex. There are many different roles that both the staff person and the person with disabilities play. Added to the complexity is the role of the family.

At the Self-determination Gathering in 2005, I facilitated a discussion on this topic. This article summarizes the discussion. While I am the person writing the article, credit goes to the people who participated in the discussions, as well as people in the past I have spoken to regarding this important topic. In these presentations, we often raised more questions than we answered.

We opened the discussion by considering the role of the staff person. The staff person can assume many roles, but he or she is generally there to assist the person with disabilities in daily living. This involves doing tasks for the person and doing tasks with the person. Sometimes the staff person may be teaching skills to the individual. We have already identified three roles: care provider, assistant, and teacher. A fourth role must also be considered- that of 'employee'. The staff person may be an employee of a provider organization, or directly employed by the person with disabilities and/or the family.

Over time, as a staff person works with an individual, friendships may be formed, adding yet another role - friend and companion. As many of us know, when we manage our friends, difficult situations can emerge. We can find ourselves torn between directing the actions of our employee, but not wanting to upset our friend. This is particularly difficult in the situation where a person relies directly on a friend for support. If you somehow

hurt or offend the friend, the friendship can end. When that friend is also a paid caregiver, the individual may be without the care and support he or she needs.

Some of the staff participated in the presentations added another role to be considered - 'advocate.' They often act as advocates for the people whom they support, working to secure proper services for the person they care for. They may also advocate for inclusion in community activities. This role as 'advocate' sometimes can create tension if the staff person has to advocate for something that is contrary to the preferences of the organizations that employ them.

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## new directions

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This raises a difficult question: Who *really* directs that staff person? Is it the person with disabilities, the family or the agency who hired them? What happens when a person with disabilities asks the staff person to do something that the agency does not want the staff person to do?

Yet another complexity may arise with family preferences and values. What if the person with disabilities wants one thing and the family wants another? One simple example comes up in the area of meal planning. What if a staff person to do when the person with disabilities wants one kind of food - french fries, for example - and the

family wants the staff person to prepare different kinds of food?

In these two sessions at the Gathering, we may have raised more questions than we answered, but these are very important questions to consider. As a part of the support process, these issues should be discussed by the team of involved parties, preferably before there is a problem. The relationships and the decision-making process need to be carefully spelled out at team and family meetings. If these meetings do not occur, it might be a good idea to start having them in a friendly, comfortable setting.

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